

RESEARCH INTO PROJECTIONS AND RETURN ON INVESTMENT ANALYSIS FOR THE UTAH PARENT CENTER

Social Services Appropriations Interim Subcommittee request

DPSD Investment in the Utah Parent Center

The amended contract between DPSD and the Utah Parent Center (UPC) agreed to five years of performance ending August 31, 2018. For all but the first contracted year, UPC provided only Family-to-Family Network (FtoFN) services. DPSD and UPC agreed upon \$495,000 to be distributed across the five year period, allocating \$104,000 for Fiscal Year 2018, the final contracted year. UPC's primary funding comes from the U.S. Department of Education's Office of Special Education Programs.

Investment Purpose

FtoFN services educate, strengthen, and support families of persons with disabilities, a mission devised over nineteen years ago by Utah families. Through the partnership with DPSD, UPC sustained a volunteer-based, statewide parent support network, employing multiple strategies including, development of a website, to help families navigate application, waiting, and use of DPSD waiver services. This peer-run network provides new and struggling families with access to similarly situated families experienced in system navigation and advocacy; and, as such, can act as a statewide natural support system. UPC underpins eleven active networks with eighteen Local Network Leaders that increase family resiliency through peer connection and education.

Peer Support Model Efficacy

Emerging peer support research in mental health (MH) settings indicate outcome improvement through multiple measurable factors useful for return on investment analysis, including:

- Reduced Use of Inpatient Services
- Decreased Hospitalization
- Decreased Costs to the MH System
- Increased Social Functioning
- Increased Empowerment and Hope
- Increased Quality of Life and Life Satisfaction
- Increased Community Engagement
- Increased Engagement and Activation in Treatment

Findings from a qualitative study (Judith Ainbinder et al, 1998), specific to intellectual and developmental disability, noted “bi-directional support seems to prevent feelings of indebtedness and inferiority and may actually lead to feelings of self-worth and empowerment.” Evidence strongly suggests that peer support helps people prevent and manage chronic conditions and challenges while increasing system engagement (Clarissa Hoover et al, 2018). Use of peer support in person-centered care shows cost-effectiveness and savings, with up to a 93 percent probability of return on investment when provided to persons with greater need and poorer initial clinical status (Peers for Progress, 2014). Economic value is highest during the initial engagement and education phase (Peers for Progress, 2014). As peer support becomes further entrenched in Utah’s social service fields, new data tracking can be developed in order to complete return on investment analysis.

Evidence of Utah’s Peer Support Need

UPC provides necessary assistance and support for the current DSPD service delivery system. FtoFN peer volunteers and UPC staff help eligible persons navigate the intake process and the waiting list, as well as, provide other supportive services. The bi-directional feature inherent to peer support increases natural problem solving capacity. Peer volunteers and paid staff provided direct assistance during 1,484 one-on-one consultations. Peers engaged in over 7,415 hours mentoring families on strategies to build caregiving capacity through effective use of community resources. This level of direct support could not be provided by DSPD employees due to the intensity and volume of need in relation to administrative workload capacity.

Peer volunteers answer the “real” questions that families have. Recurrent anecdotes from community partners indicate that families have questions that they are too embarrassed to ask DSPD employees. Caregivers may not want to appear unable or uneducated in front of “the experts,” and will often not ask for needed clarification. But they will ask a peer.

Enrolled families may ineffectively use services, especially self-administered services, because they lack the language needed to communicate with contracted support coordinators. A caregiver, with a lack of descriptive language and jargon, perceiving their difficulty articulating assistance needs as a burden to their support coordinator, will not seek help from the accessed state service. But they will talk to a peer.

Future Partnership Opportunity

Technological innovation in DSPD service delivery offers future opportunity for the FtoFN to continue providing cost-effective peer support services. Families engaged with intake and waiting for services will need help learning to use My System for Tracking, Eligibility, and Planning Services (MySTEPS). Web-based innovations improve engagement and satisfaction over the long-term, but interaction with a new system comes with a learning curve. The established UPC electronic communication system of email, listserv, newsletters, and social media currently used for technical assistance should easily absorb MySTEPS troubleshooting. FtoFN peers can offer user experience (UX) troubleshooting from the perspective of and in the language of the user rather than the developer. Peers will answer the “real” questions that families avoid asking DSPD employees.

References

Clarissa Hoover et al, ISSUE BRIEF: A FRAMEWORK FOR ASSESSING FAMILY ENGAGEMENT IN SYSTEMS CHANGE, Lucile Packard Foundation for Children’s Health (April 2018).

Clarissa Hoover et al, LITERATURE REVIEW: FAMILY ENGAGEMENT IN SYSTEMS, Lucile Packard Foundation for Children’s Health (April 2018).

Elizabeth Willis, *Quantifying the Benefits of Peer Support for People with Dementia: A Social Return on Investment (SROI) Study*, 17 Dementia 266-278 (2018).

Judith G. Ainbinder et al., *A Qualitative Study of Parent to Parent Support for Parents of Children with Special Needs*, 23 Journal of Pediatric Psychology 99-109 (1998).

Peers for Progress, GLOBAL EVIDENCE FOR PEER SUPPORT: HUMANIZING HEALTH CARE, American Academy of Family Physicians Foundation (2014).

Peers for Progress, ECONOMIC ANALYSIS IN PEER SUPPORT: BREADTH OF APPROACHES AND IMPLICATIONS FOR PEER SUPPORT PROGRAMS, American Academy of Family Physicians Foundation (2014).

SAMHSA, Section on Programs & Campaigns, *BRSS TACS*, https://www.samhsa.gov/sites/default/files/programs_campaigns/brss_tacs/peer-support-2017.pdf, (last updated 11/20/2017).

Strengthening Families, *The Strengthening Families National Network*, Center for the Study of Social Policy, available at <https://www.cssp.org/reform/strengthening-families/SFNNsummary.pdf>.

Utah Parent Center, Section on Projects, *Family to Family Network*, <http://www.utahparentcenter.org/projects/family-to-family/> (last visited May 23, 2018).

Utah Parent Center recorded data for reporting period Sept. 1, 2013 - Feb. 20, 2018, pursuant to DSPD Contract #146109.